Chapter 1
Introductions

A Tale Of Two People

Two people were brought to the emergency room today. Each suffered from a heart attack. Here is what we know about them.

The first person:

- Has many other illnesses;
- Has no health insurance and no medication;
- Is unemployed;
- Has no money;
- Does not go to doctors;
- Is homeless;
- Is hungry;
- Is very stressed and distressed;
- Has always had poor nutrition;
- Lives in a hazardous place with polluted water, polluted air, and toxic wastes;
- Has little education;
- Does not speak the standard dialect;
- Experiences social rejection;
- Has a minimal support system.

The second person:

- Has no other illnesses;
- Has health insurance and access to medication;
- Is employed;
- Has money;
- Goes to doctors;
- Has a home;
- Is not hungry;
- Is not very stressed or distressed;
- Has good nutrition;
- Does not live in a hazardous place with polluted water, polluted air or toxic wastes;
- Is educated;
- Speaks the standard dialect;
- Does not experience social rejection;
- Has a good support system.

Is The Illness The Same For Both People?

What is the prognosis for these two people?

Does this illness exist in the same biological environments? Psychological environments? Physical environments? Social environments?

How do we measure the impacts of these environments on a person's health?

A Tale Of Two Communities

There are two communities in the town. Here are their situations.

The first community:

- Has suffered for generations from the racial and cultural prejudices of the dominant culture;
- Is still the target of racism: institutional, personalized, internalized, and cultural;
- Has poorer health in general;
- Has high poverty rates;
- Has high unemployment rates;
- Has fewer occupational opportunities;
- Experiences forced isolation;
- Has poor access to health care, jobs, or schooling;
- Has high rates of homelessness;
- Has high rates of poor nutrition and hunger;
- Experiences high rates of stressful events;
- Has cultural roots – values, philosophy, attitudes, behavior, spirituality – that are different from, and rejected by, mainstream white America.

The second community;

- Has not experienced abuse due to racial and cultural prejudices;
- Is not the target of racism;
- Has better health in general;
- Has low poverty rates;
- Has high employment rates;
- Has many occupational opportunities;
- Does not experience forced isolation;
- Has good access to health care, jobs and schools;
- Has low rates of homelessness;
- Has low rates of poor nutrition and hunger;
- Experiences low rates of stressful events;
- Has mainstream cultural roots.

Is Illness The Same For Both Communities?

What is the prognosis for these two communities? Does illness exist in the same biological environments? Psychological environments? Physical environments? Social environments? How do we measure these environmental impacts and circumstances on a community's health? Might the causal factors that affect health in these two communities act differently?

"If we want better health, we need a new map, a new way to work together."

Two people, two communities, provide stark and simple contrasts. In reality, there are many people and many communities. There are many paths leading to health and illness for individuals and for communities. Treatments that work well for one person may not be necessary or sufficient for another. Programs that work well in one community may not work in another. How do we, as evaluators, capture the differences between these communities? Can we make any kinds of generalizations or are they really different kinds of entities? Maybe, we should be making comparisons among similar communities, for example, Native American communities compared with other Native American communities, and not with middle-class, white American communities. The dynamics, the environments, the pressures, the circumstances, the history, the culture itself, are different.

Community-based initiatives should be culturally sensitive and tailored to the true underlying issues that contribute to poor health outcomes for a given community. Evaluation should be community-based, too. The people and organizations that develop new approaches to promote health at the community level should also take the initiative in deciding how to evaluate those efforts. They have the clearest sense of what the program is designed to achieve and how success will occur. Evaluation should provide information that strengthens the program and improves its chances for success. Evaluation methods for culturally diverse programs should have three basic goals. The first is to do no harm. The second is to be helpful and constructive. The third is to remember the context.

The Eye Of The Elephant:

Cultural Perspectives On Evaluation And Communities

Pauline E. Brooks, PhD
California Endowment

Our current evaluation methods have a heavy European cultural influence. The evaluation models, the concepts and language, the research literature, the administrative rules and the tools all reflect a scientific, analytic Western approach. We have concepts; we have tools; we have assumptions; we have language; but these all rest on a particular kind of culture. The cultures that have generated these methods are not the cultures in which we are making evaluations of racial disparities. Our tools do not measure what we want to measure when it comes to changes in health disparities, because the meaning of the factors that contribute to health disparities differs among communities and cultures. There are alternatives for evaluating change. These alternatives are not better or worse than the present evaluation methods; they do not replace present methods: they are different. They emerge from the cultures of the people that the

programs serve.

Culturally relevant alternatives complement traditional evaluation paradigms, models, tools, concepts, language, and approaches, and expand them to include the worldview of the communities and their people.

The Blind Men and the Elephant

Not so long ago, a large gray elephant stood eating the lush greenery in the ancient walled garden of the Rajah's palace. He paused for a moment, and trumpeted loudly at the sight of six blind sages who were walking past in single file, each with his hand on the shoulder of the man before him.

"What made that sound?" cried the first sage.

The second replied, "I believe that is the sound of an elephant."

"What is an elephant?" asked the third.

"I am not exactly sure," said the fourth.

"I have never seen an elephant," said the fifth.

"Let us investigate," the sixth wise man boldly proclaimed.

The first blind man walked forward with fingers outstretched until he came to the side of the elephant. "How smooth and firm is this! An elephant is like a wall!"

The second wise man reached out and touched the trunk of the elephant. "How round it is, and so flexible in its movement. The elephant is just like a snake!" The third blind man walked directly into the elephant's tusk. "Ow! How sharp and pointed the elephant is! It is like a spear!" The fourth blind, wise man grasped the elephant's ear. He moved his hand along its surface, and jumped back as the elephant flapped its ear. " How wide and supple is the elephant! How cooling are its breezes! An elephant is like a fan!"

The fifth blind man went forward until he reached the elephant's knee. He reached around with his right arm. He reached around with his left arm. "How round and tall is the elephant. An elephant is like a tree!"

The sixth blind man strode up to the elephant's tail. He grasped it firmly and announced, "How thin and long the elephant is, very much like a rope." The sages fell to arguing among themselves. "The elephant is like a wall." "No, a snake!" "Not at all like a snake or wall – it is a tree!"

"Not a tree! An elephant is like a fan!" "It is a sharp spear!" "No, a rope!"

With billowing minds and bellowing mouths, To opinions these blind men held fast.
While the elephant stood, quite undefined, In his garden of ancient past.

Source: Adapted from: Lillian Quigley, *The Blind Men and the Elephant.*, New York: Charles Scribner, 1959, and Heather Forest, *Wisdom Tales from Around the World*. Little Rock: August House Publishers, 1996.

When we apply evaluation methods to community programs, we single out specific measures that will give us indications about the effectiveness of the program and its results. Our description of the program may be clear. The evaluation methods we choose may be scientific and appropriate. The measures may be accurate, valid and reliable. Even so, we may miss the meaning of the program, and its real impacts on the people it serves. We need the big picture of the community to evaluate the importance of the specific program. It is important for us to hear from the people themselves.

This means we must shift our approach to evaluation. We must seek multiple perspectives across multiple disciplines and coordinate the data from these multiple perspectives to get a better picture. We must get inside the "elephant" (community) and generate assumptions; develop and test hypotheses and theories; based on what the elephant sees, experiences, knows, feels, struggles with, and believes. To do justice to the communities and programs that we are evaluating, to really understand the health problems, we need to understand the environment and the perspective of the people of the community.

There are some fundamental flaws in the project paradigm that funds many community-based programs. Money is given to communities for a limited time period, to do some specific intervention, and show immediate results. This leads communities directly into a "trick bag," where the rules are designed by sponsors and evaluators. The trick bag has a lot of complexity in it. The trick bag asks community-based organizations (cbo's) to instantly implement services, to do evaluations, and to somehow at the end of three or four or five years, to have some type of scientific evidence that something has changed. Now, if in 300 years, people of the communities have not been able to do that, it isn't likely that they will succeed in two years or five years. It probably will not happen. Or, not happen in a way that evaluators and sponsors would accept as hard scientific knowledge. That's a trick bag. We are setting communities up, and we're setting the people up, for expectations that logically and realistically and historically probably cannot happen. Especially when these community-based organizations have other constraints. They design programs to fit the requests for proposals, and not to fit communities' needs.

How To Recognize And Get Inside The "Elephant"

As social scientists and evaluators, we need to begin to develop a whole new way of including the perspective from inside the "elephant" (community). We cannot solve the problems of racial disparities in health until we can take that perspective, because we are operating on limited information. Factors that characterize culturally isolated and racially segregated communities must be included in program evaluations. Racism, substance abuse, and environmental hazards each play a part in our communities, and must be considered as part of the "big picture". We need to explore non-linear and non-individualistic models. Our logic models tend to be linear. We think in linear ways: "this causes that". Community people rarely talk about health behavior in a linear fashion. It is a whole person and a whole community that is the appropriate model.

Issues should be studied in clusters as they occur, not examined in isolation. We need to be funded to listen, learn, and be guided by the culture of communities. The key is a process of informed observations. This means more than sitting as a passive observer. It requires a community guide who can accurately explain and interpret the information.

Fair comparisons need to be made among communities with similar racial and cultural characteristics. There are communities where health problems are less frequent. These communities can be compared with similar communities where there are very serious problems. We need to study health systems and follow people as they go through these systems. What happens as people of color go through institutions for care? What is the reality as one goes through the health system from beginning to end? Discrimination takes many forms, and has the potential to affect care at many points. If people get the message that they are not wanted from the person at the reception desk or the nurse, then they may not be compliant with treatment. The whole process needs to be considered. Evaluation efforts need to assess protective factors as well as hazard factors. An ecological perspective is important.

Programs should not have to make unrealistic promises for what can be accomplished with limited funding for limited time periods. Sponsors should plan to support community-based initiatives for a "fair trial period" – that is, for sufficient time for real change to occur. Few interventions have instant success.

The Culture Of Evaluation Science

Private, public, and philanthropic sources of funding for community-based health programs are influenced by a culture of science that adheres strongly to two principles: evidence and attribution.

Decisions about evaluation measurement and design, and consequently the support of particular intervention evaluation strategies, are driven by underlying assumptions about what constitutes "evidence" and what methods will allow observed effects to be "attributed" to the interventions in question.

Credible evidence is understood to be quantitative measures with proven degrees of validity and reliability, although acceptance is increasing for mixed method strategies that integrate qualitative and quantitative techniques.

Likewise, those who sponsor health programs expect to be able to attribute outcomes to a given intervention by controlling for sources of confounding. This remains the greatest methodological challenge facing community-based evaluators.

Marshall W. Kreuter, PhD

What Needs To Change?

A Conversation Of The CENTERED Project's Blue Ribbon Panel, August 2000

Pauline E. Brooks, PhD
The California Endowment

There is an underside to community-based initiatives. These communities have been pretty much throw-aways in this society. These were not communities that were loved and nurtured and cared for and valued. Community people know this, even if they never read a book. Given that history, why now?

The United States government, social scientists and professional evaluators, program people, we're not innocent in the creation of circumstances that communities experience. The data that we collect may be used for unintended purposes. There needs to be some protection for the community. Who will have access to the data? Agreements need to be made before researchers come in and collect information. Maybe we don't have to ask certain questions. For example, in work with immigrant populations, even if it is key to my hypothesis, I do not ask where people were born, since this information may be used against the people who are sharing the information.

The approach of trying to change one specific aspect or address one specific health problem does not really meet the communities' needs. For example, a program may be designed to address diabetes and evaluated to show some evidence that scientists will accept. That is wonderful, but what about all the rest of the health problems and the other problems that exist in our communities? Are you just trying to change one thing and leave everything else intact? That may sound good from a research perspective because we can control for things, but that does not sound good from a community perspective. How are existing health models and practices really not serving, actually actively under-serving, these populations? There are many other things that need to be examined.

Hank Balderrama, BSW, MS
Washington Dept of Social Services

We need to phrase things in the way that makes sense to people, that shows that not only are these factors harmful to people on a personal basis, but there are also some good social and economic reasons to do things differently. We can demonstrate that there are some human and financial benefits in giving people permission to do the right thing. I think that is a solid approach and one which is very difficult to argue with and very powerful, and which robs nobody of their dignity.

Joann Umilani Tsark, MPH
Papa Ola Lokahi

Change has to occur in a lot of places, but a main place is the establishments and institutions that fund interventions and then the evaluations of them. A lot of organizations that are funding work to address racial and ethnic disparities in health have a focus on specific diseases. Look at REACH. It is a disease, body part, condition-focused Initiative. The National Institutes of Health are certainly driven that way. Think about the groups that are trying to get money to do this kind of work. They have to write proposals. It is all this linear thinking, the traditional ways of thinking.

What are you going to try to do? What is your logic model? What is your intervention going to do? How are you going to measure it? How are you going to prove it? Communities are being given resources to reduce disparities, but they must fit into this traditional way of thinking about doing research. Before anything is really going to change, we have to change the way in which the whole thing is conceptualized and resources are given to fund these kinds of initiatives.

Paula M. Lantz, PhD
University of Michigan School of Public Health

Communities have to change, too. One of the lessons for communities is to not jump at every carrot that is out there. It is really hard, because communities want to respond to so many pressing problems. It is very tempting and there is a lot of need. The things that have succeeded in communities have been things that have been thought out. It takes time. Rarely do funders acknowledge the time it takes to bring about sustained change.

Doug Easterling, PhD
University of North Carolina at Greensboro

Evaluators need to change. The culture that defines "evaluators" has strong implications. The positivistic, empirical approach that science traditionally has brought to research, and that researchers have then brought to communities, has really impeded any kind of exploration or dynamic development of these contextual solutions. Everything that researchers do is to reduce it: reduce it down to individual logic chains; reduce it down to individual causal factors; reduce it down to individual outcomes. What communities need is to keep it big. Keep it at the level where you get real solutions, and that means that evaluators have to accept their own limitations.

Quinton Baker
Community Health, Leadership and Development

I think a significant change has to take place with community-based organizations and the role that they play in terms of evaluation and in terms of the initiatives. Oftentimes, community-based organizations partnering with academic institutions or health agencies, allow those agencies to take the lead, allow them to set the tone for what is happening. This is particularly true with evaluation, because it is an area that we have shied away from or not wanted to be bothered with. So, I think one of the places that the impact has to happen is with community-based organizations. It is their ability to understand this idea of measuring their success in their community. And then, how they communicate that to CDC and other sources.

Deborah Jones-Saumty, PhD
American Indian Associates

One of the things that I try to do when I work with Indian Tribal communities is to encourage behavioral reciprocity. What that does is help the community feel that it is all right to move from being acted upon, to being an actor. That is very difficult for some communities, and some communities are not ready for that change. But the concept of behavioral reciprocity, I think, would apply to a number of communities of color, because many have been acted upon for generations. In some cases, if you simply give them permission to go from acted upon to being an actor, they can do it with no problem. Others will need much more guidance in terms of what it means to be an active participant in this change that we're talking about. So, I think we have to be ready to look at all levels of readiness for

change within those communities.

Belinda Reininger, DrPH
University of Texas-Houston
School of Public Health at Brownsville

I think what should change is that evaluation would actually be useful to communities. They would see evaluation information as important, not irrelevant and just something they had to do. I think that we, as programmers, evaluators, and communities would work in partnership over the long-term. We would stop seeing these three-year partnerships, or the partnerships to get a proposal funded. We would start seeing long-term networks. We would assess clusters of appropriate factors rather than individual factors; we would recognize and measure the impact of the contextual factors in our work. We, as evaluators and programmers, would recognize that our primary audience is the community and that we are accountable to the community first.

Quinton Baker
Community Health, Leadership and Development

The interesting thing to me is that, of the tools that I have looked at, all stick very much to a traditional model of evaluation. There is nothing out there that even introduces any of the concepts suggested here.

Jerry Del Gimarc, MA
South Carolina Turning Points

The typical funding sources want to see change and something concrete within a limited amount of time. That is not what we're talking about. We want to clarify what is community capacity, and how you would measure that. The other part is to look at really a whole different way of assessing the community's strengths and the community's situation.

That's not in any of the tools that we typically see. We need tools that include community history and community expectations, hope and sense of power and so forth. That is a whole different thing, because the assessment tools that you see are pretty standard for more organized programs. We want to understand clearly what the community sees as it's principle outcomes or statements of success, which might be different from the funder's. What do communities say is their success?

Bobby Milstein, MPH
Centers for Disease Control and Prevention (CDC)

I think one of the difficulties is that there is a chasm between what funders want and what communities see as successes. The community has not had the ability to articulate what they are doing and the successes, and have not had the power to influence what it is that funders are demanding to come out of communities. Until communities can really articulate their successes, and can really identify their issues, it will be difficult to bring about change.

Pauline E. Brooks, PhD
The California Endowment

Communities are doing a whole bunch more than anybody ever knows about. They have other kinds of capacities that we don't even recognize for functioning.

Doug Easterling, PhD
University of North Carolina at Greensboro

So, what you're saying is that there is almost an implicit social change model that

communities work under that has never been validated, never been documented. If communities were able to do it, you could almost hang a scientific term on that.

Hank Balderrama, BSW, MS
Washington Department of Social Services

The academic community, the government community, the private funding community, the community-based organizations, they don't all talk the same, and they don't have the same values regarding efforts and how we document them. We need to have some way for those folks to communicate and understand.

Christine Lowery, PhD
University of Wisconsin

Communities are speaking. Women gathered on porches and family groups are talking about problems and issues of the community, but it is not taking place in the context of a community meeting. They are discussing things with family members and how they are involved with certain things. But, I think that there will be pathways.

There is a developmental progression in learning evaluation, which includes strengths of the community and strengths of individuals in the community and leadership in the community. You have pathways to evaluation. You start where the clients are, so that there are multiple starting points.

We could produce a guide such that somebody could recognize themselves in the examples that we've given, and say, "we're doing this," and we could integrate that into a model. Communities could already see that they are functioning. I think that would prove useful, so that you can see yourself. That's what I envision. It is an integrated analysis, a picture. It's visual, so that communities can see where they are and where they can go, with one glance, and have some understanding.